

WHAT ABOUT CONFIDENTIALITY?

Strict policies and procedures have been developed to serve as guidelines for maintenance of confidentiality and disclosure of data. Hospitals participating in MCR retain control over their data. Access to confidential information on summary data is allowed only by agreement with participating hospitals.

Data collected on each patient include:

- Patient identification
- Site of disease(s)
- Tumor histology
- Stage or extent of disease(s)
- Treatment performed or initiated
- Current status of patient
- Length of survival
- Family history of cancer
- Tobacco and alcohol use
- Occupation and industry
- Unusual toxic exposure

IN SUMMARY . . .

The Missouri Cancer Registry serves a twofold purpose:

1. It is a tax-supported service to individual hospitals and their health care personnel.
2. It maintains a centralized database documenting cancer incidence.

FOR MORE INFORMATION CONTACT:

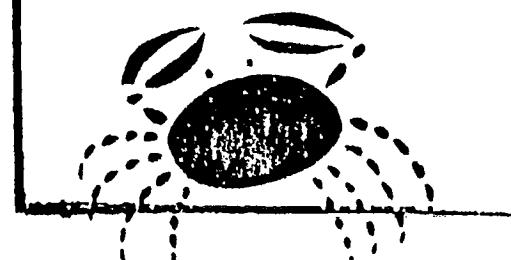
Missouri Cancer Control Program
 Missouri Cancer Registry
 Business Loop 70 & Garth Avenue
 Columbia, MO 65201
 (314) 875-2218 or 2219

Department of Social Services
 MISSOURI DIVISION OF HEALTH
 Bureau of Chronic Diseases

AN EQUAL OPPORTUNITY/
 AFFIRMATIVE ACTION EMPLOYER
 services provided on a nondiscriminatory basis

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Missouri
 Division of Health
 Cancer Registry



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WHAT IS A REGISTRY?

A cancer registry is a system for collection, storage, analysis, and interpretation of information on cancer and cancer patients. It may include data on premalignant lesions and certain benign tumors as well as on malignant neoplasms. Cancer registries are either hospital-based or centralized; the difference lies in scope.

The Hospital-Based Registry: The hospital-based cancer registry may be an autonomous unit or a section of another department. Using information obtained from medical records, the hospital registry provides immediate access to cancer data—such as exact number of diagnoses in a given time period or relative frequency of cancers by site.

A hospital-based survival registry allows for active lifetime follow-up of cancer patients diagnosed or treated in that hospital. Registry data can also assist in evaluation of survival rates. Diagnosis, treatment, and staging data can provide persuasive documentation for additional hospital personnel, equipment, and facilities.

The Central Registry: A central cancer registry depends on data obtained from hospital-based registries or other sources. A statewide system maintains data on a large enough population to make statistically significant analyses of cancer incidence and prevalence. As research turns more and more to investigation of environmental, occupational, and lifestyle factors in cancer incidence, the population-based registry's role in epidemiological assessment becomes increasingly important. Clinically, the central registry can play a significant role in providing analyses of data on individual patients or groups of patients to assess efficacy of diagnostic and treatment practices.

THE MISSOURI CANCER REGISTRY

The Missouri Cancer Registry (MCR) is a central cancer registry system operating since 1972 in cooperation with hospitals throughout the state. MCR is a major component of the Missouri Cancer Control Program within the Bureau of Chronic Diseases of the Missouri Division of Health. The Program maintains liaison with the American Cancer Society, the American College of Surgeons, and with national, state, and regional medical record and tumor registrar associations.

In 1983, a bill mandating cancer-incidence reporting on every hospitalized cancer case was signed into law. The law provides shared responsibility for reporting between the physician, who makes required information available to the hospital chief executive officer, who reports this information to MCR. Data on occupation, family history, personal habits and unusual toxic exposures are among the required items. Subsequent reports on each cancer case are not required by law; however, MCR encourages hospitals to follow their patients annually and to voluntarily submit follow-up results.

WHAT DOES THE MISSOURI CANCER REGISTRY PROVIDE?

Data Processing: Provides a computerized system for storage and retrieval of cancer specific information; generates special listings and reports as requested by participating hospitals.

Consultation: Serves as a resource to hospitals initiating registry operation; provides annual workshops for hospital-based registries; consults with hospital-based registrars on routine problem solving and data quality assurance; assists in meeting requirements for approval of a Hospital Cancer Program by American College of Surgeons.

Materials: Provides free of charge all forms and many of the reference materials required for hospital-based registry operation.

Evaluation of Care: Can assist in systematic follow-up of cancer patients; permits each hospital to evaluate its diagnostic and treatment practices.

Administrative Planning: Establishes a data base for justification of hospital facilities, equipment, and personnel involved in cancer care.

Statewide Cancer Database: Examines trend in cancer incidence, therapy, and patient survival; provides data for epidemiological studies to identify environmental risk factors; assists in evaluation of overall effectiveness of public interventions such as education and screening programs.



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